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This is the author version published as:

Carroll, Julie-Anne and McCarthy, Rebecca (2010) *Geekdom for Grrrls health : Australian undergraduate experiences developing and promoting women's health in cyberspace*. In: International Conference of Education, Research and Innovation Proceedings, 15-17 November 2010, Convention Centre - Melia Castilla Madrid, Madrid.

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GEEKDOM FOR GRRRLS HEALTH: AUSTRALIAN UNDERGRADUATE EXPERIENCES DEVELOPING AND PROMOTING WOMEN'S HEALTH IN CYBERSPACE.

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Keywords: women, health, ICTs, undergraduate, curriculum, pedagogy, Australia.

Introduction

There is an increasing global reliance on the Internet for retrieving information on health, illness, and recovery (Sillence et al, 2007; Laurenta et al, 2009; Adams, 2010). People suffering from a vast array of illnesses, conditions, and complaints, as well as healthy travelers seeking advice about safe practices abroad, and teens seeking information about safe sexual practices are all now more likely to go to the Internet for information than they are to rely solely on a general practitioner or physician (Santor et al, 2007; Moreno et al, 2009; Bartlett et al, 2010). Women in particular seek advice and support online for a number of health-related concerns regarding issues such as puberty, conception, pregnancy, postnatal depression, mothering, breast-cancer recovery, and ageing healthily (van Zutphen, 2008; Raymond et al, 2005). Consequently, there has been a growing body of research investigating which groups of women are more likely to utilize the Internet for health information, what their specific health concerns are, and importantly, how they search and select information from a vast range of sources and websites (Sillence et al, 2007; Perez-Lopez, 2004; Woodlock, 2005; Ziebland, 2004; Kalichman et al, 2002; Toub, 2001; Fredriksen, 2008; Dey et al, 2008; Pandey et al, 2003). Some of the key areas of information on health sought by women include pregnancy-related concerns (Zutphen et al, 2008), HIV/AIDS (Kalichmen et al, 2003), cancers (Zieband, 2004), depression and anxiety (Woodlock et al, 2005), and menopause (Perez-Lopez, 2004).

Many researchers have been highly critical of medical advice on the web, as much of it is commercially driven. For example, Woodlock (2005) found that companies marketing anti-depressants to women provided invalid and unreliable online tests for mental illness in the process of trying to convince more women that they needed medication. Perez-Lopez (2004) concurred that 'medical information [on the web] is of low quality and is biased towards commercial goals' (p. 276) in his study into the use of the Internet by women seeking information regarding menopause. Ziebland (2004) makes the case that the Internet encourages women to become their own 'health experts' and to 'self-medicate', which can be dangerous in the treatments of cancer (p. 1785). However, this case highlights the growing urgency for reliable and correct information to be available to women

searching online for health advice. Toub (2001) makes the point that many women who choose Internet forums for health advice are after highly individualized support and guidance, and not 'general truths' or evidence about women's health – which they seek and gain from a physician, thus distinguishing both a difference in what women seek and what they expect to get when they seek information online versus in a physician's office. Pandey et al (2003) argued that women use the Internet for health information for three key reasons – firstly, to seek out health promotion in a proactive sense, secondly, if they have high level health needs or are chronically ill, and finally to save on medical costs. This concurs with Dey et al (2001) findings that women in Sydney Australia, were very likely to use the Internet prior to a mammogram test, which is a time of an acute health need that women seek free access to in local clinics.

While much research has focused on how the Internet provides and mediates communication on specific health issues, some studies have investigated *how* women use the Internet to choose information upon which they will act (Sillence et al, 2007; Zutphen, 2008). That is, studies have sought to find out what aspects of design, aesthetic, information arrangement, and content convince women to either select or reject information from a website. Sillence (2007) made some useful findings in this regard. They found that many women will reject important and high-quality information on the Internet due to poor design, and will 'act like scientists' using web materials to generate and test theories about health-related treatments (p. 1853). Ultimately, they found that women integrate online health information with advice from friends and family, and still view their physician as their primary and final source of expertise. This growing body of evidence to show that many women regularly rely on the Internet for information about a myriad of health issues, and that they are discerning in their acceptance and rejection of advice (albeit this process largely based on web-design and aesthetic) sits in agreement with many of the social theories and movements that have been around since the 1990s regarding the issues of democracy and self-initiative introduced and strengthened by the Internet. The emergence of the Internet as a sophisticated tool promoting communication across traditional social hierarchies, geographies, social groups, and information genres generated many social theories regarding the dismantling of existing social structures, the undermining of traditional orders and authority, and the liberation of people via a tool that gave them access to people and places they would not normally be able to access (Stengrim et al, 2005; Mumby, 2006; Bowker, 2001). It was argued in the postmodern sense that online communication, or technologically mediated communication challenged all grand narratives, and led to social complexities, paradoxes and contradictions that rendered prior critical theories such as second wave feminism, Marxism, and Socialism redundant. Overall, inequalities were appearing to be redressed via technology, rather than the blood bath of a revolution initially prescribed by activist groups concerned with the overthrow of dominant groups in society, but more specifically those that dominated under Capitalism.

This had interesting consequences for feminism and for women. Specifically, a social movement called 'The Riot Grrrls' emerged, which initially derived from an feminist underground punk scene in the 1990s, but which spread to other more mainstream domains, and whose philosophy was based around the important of Do-It-Yourself (DIY) for women. That is, this third wave movement, or post-feminist bent was driven by the shattering of grand narratives – including a shift away from second wave feminism - and the rise of more anarchic and individual approaches to progressing the well-being of women (Lather, 1991; Fay, 2007; Gregg, 2006). These ideas that women could and should

focus on individual action to take charge of their destinies was greatly fuelled by the arguably more open, accessible and democratic forum of communication afforded to them by the Internet: women could now seek, select, reject and discuss social and health issues that concerned them with anyone in the world just by accessing a computer. Thus, an emergence is apparent between third wave feminism (grrrls online), postmodern social theories driven and affected by new inventions in communication technology in the past two decades, and the growing body of empirical evidence showing that women require high quality data sources regarding their health to be available online and in conjunction with advice provided to them by a practitioner.

In keeping with this increasing socio-technological trend, the Women's Health Unit at the Queensland University of Technology (Q.U.T), Brisbane, Australia, introduced the research, design, and development of online information resources for issues affecting the health of Australian women as an assessment item for students in the undergraduate Public Health curriculum. Students were required to research a particular health issue affecting Australian women, including pregnancy, pregnancy terminations, postnatal depression, returning to the work force after having a baby, breast cancer recovery, chronic disease prevention, health and safety for sex-workers, Indigenous women's health, and ageing healthily. Students were required to design and develop websites that supported people living with these conditions, or who were in these situations. The aim of the task was for students to design websites for communicating effectively with both women seeking information about their health, and their health practitioners. The students used three key strategies to guide their website design and implementation: firstly, they researched the specific area of women's health that they were promoting; secondly, they unearthed the latest findings in effective writing and design for the web, and finally, they gathered empirical evidence from peer-reviewed journal articles regarding how women search for health information on the web. The pedagogical challenge inherent in this exercise was twofold: firstly, to encourage students to develop the skills to design and maintain software for online health forums; and secondly, to challenge public health students to go beyond generating 'awareness' and imparting health information to developing a nuanced understanding of the worlds and perspectives of their audiences, who require supportive networks and options that resonate with their restrictions, capabilities, and dispositions. This latter challenge spanned the realms of research, communication, and aesthetic design. Students were required to present their websites, as well as their research for grading by a panel of academics in the area of Women's Health research. Students were also required to answer a series of questions in writing as part of a reflection on their learning. A data analysis was conducted on the students' reflections using grounded theory techniques, and developed into a theoretical framework for future teaching initiatives combining communication technology and health, depicting the challenges involved in designing health communication for women online.

Method

Participants

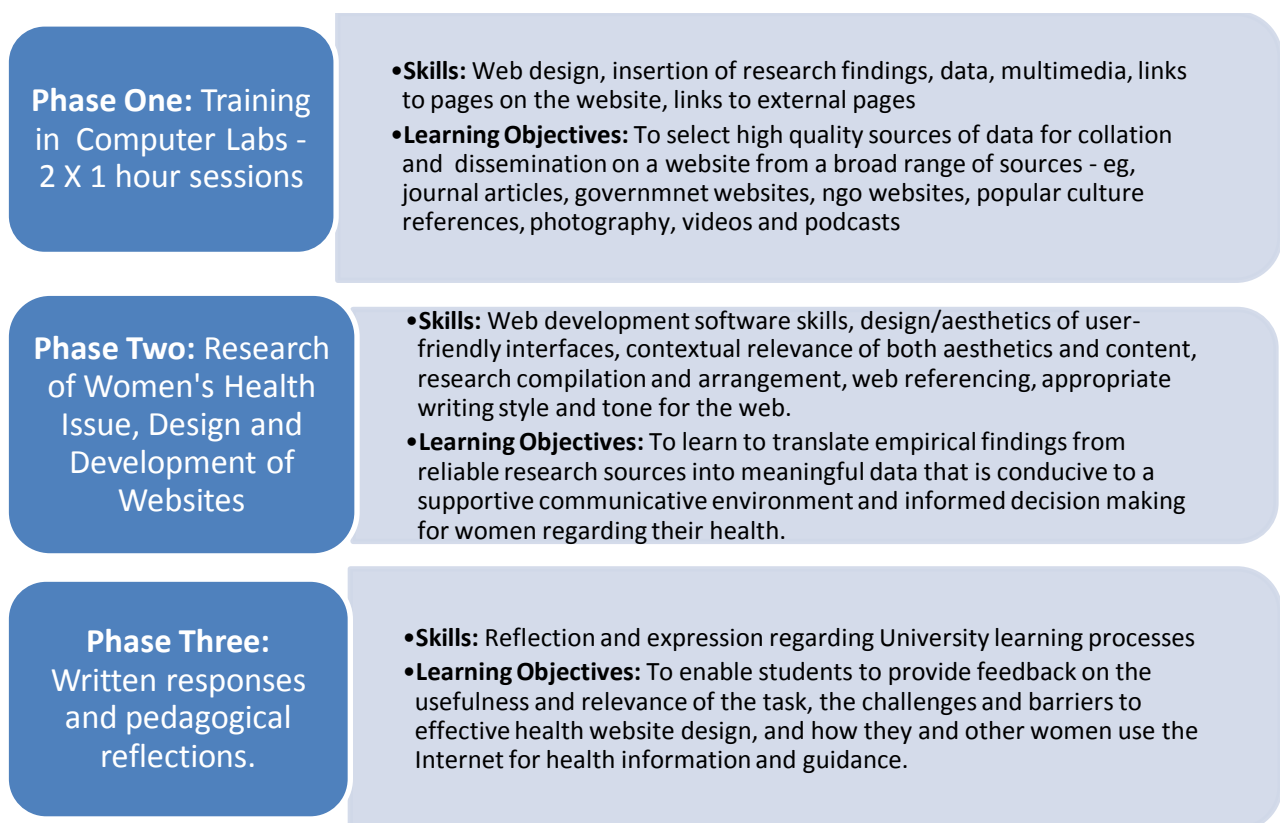
40 undergraduate students majoring in the Health Sciences, and who were enrolled in the Women's Health Unit were required to participate in this learning exercise as part of their Undergraduate Degree at the Queensland University of Technology (QUT), Brisbane, Australia. All students were female, and ranged in age from 18 to 50 years. None of the enrolled students had engaged in an

exercise such as this prior to this set task. None of the students had had previous training in writing for the web, website design, or web implementation. All students were either in their second or third year of their Undergraduate degrees.

Design

The design of this exercise was set out in three key phases. Firstly, students were trained in the area of web design and development. This stage involved research and investigation into this area of expertise as well as practice in computer laboratories. Secondly, the students were required to design and develop websites into their chosen area of Australian women's health. Again, this phase involved much research into the health issue itself, and social marketing strategies in that particular field, as well as data on how women used this kind of information online, if at all. Finally, students responded to a number of set questions in writing about the learning processes, which served as data reflections on the pedagogical stages involved in the task. **Figure 1** below depicts the study design that was implemented in this teaching and research exercise.

Figure 1. Design of Teaching and Research Task into the Design and Development of Websites for Women's Health



Procedure

Phase One

Students enrolled in the Women's Health undergraduate unit were provided with two one-hour sessions in a computer laboratory on the QUT campus wherein they were taught the technological

skills required to design a women's health website. The students were given the option of using the Microsoft Publisher Program, or any free online web development program, such as Google Pages. They were taught to design and insert content based on their own research, insert images, develop links to other websites and embed links to videos – either their own, or existing ones on Youtube. Teaching students these skills in the computer laboratories allowed them to draw on different research and media to communicate effectively with women about their health. The students also were required to research the latest findings on effective web-writing, and the relative importance of both aesthetic design and the quality of the information being provided.

Phase Two

Students developed their websites individually. The topics they were permitted to choose from included support for women with breast cancer, support for Indigenous pregnant women, support for women contemplating pregnancy termination, support for workers in the sex-industry, support for women returning to work after having a baby, and support for women with ovarian cancer. Each student chose the software program they were most comfortable working with. Their task was to combine in-depth research on a particular health issue with their knowledge regarding how women use the Internet for health issues, and what works in terms of website aesthetics, design, and content delivery amongst different social groups. They submitted their final products via email or portable USB key, and all websites were saved onto a central site with the help of IT support services. The websites were viewed and graded from this central location. Assessment criteria included structure and logic, web aesthetic and design, theoretical framework, communication tone and style, scientific research/content, and overall usability, usefulness, and relevance to women and health care professionals.

Phase Three

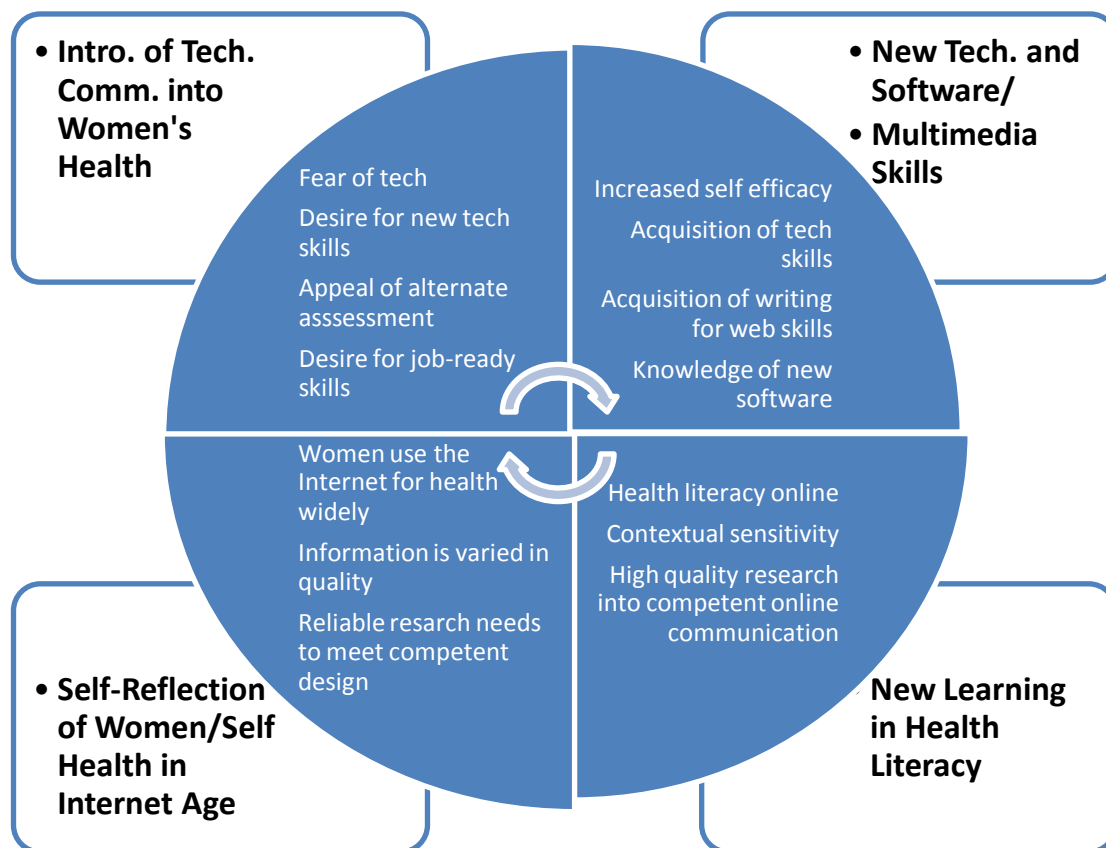
Finally, the students were asked to answer three open questions about their learning processes during this task, and to reflect in writing on the knowledge they had gained from researching their women's health issues, and designing and developing their online health resources. The first question focused how they initially felt when presented with the task, and how it related to the rest to their other subject content and assessment items. The second question aimed to unearth the key learning processes and new skills acquired during this assessment. The third question asked them to reflect on how women use the Internet for health information and services, and what the current challenges are for people designing this type of information, as well as for health practitioners who are now often the second, not the first sources to be consulted for health related information. These reflections were treated as pedagogical data which was analyzed and developed into a model regarding the processes involved in designing effective and appropriate health advice for women on the Internet.

Data Analysis

All 40 written reflections were collected from the students. Each set of answers to the three questions regarding the design of online information for women's health constituted two to three pages (around 500 word) responses from the students. Just over one hundred pages of written text in total were available for analysis. The written reflections were imported into NVivo for analysis. A social constructionist approach to grounded theory analysis was used to analyse the data (Charmaz, 2006, Carroll et al, 2008, Glaser, 2003). A grounded theory approach was taken as we aimed to find out by asking open questions of the data such as *'what is being reported here?'* and *'what is going on in*

students' comments about their learning experiences?' In keeping with the aims of this exercise, which was to find out the perspectives of those learning to create effective websites for women's health, it was important to take a more social constructionist approach to grounded theory, as this approach allows greater recognition of the subjectivity inherent in both the reporting and the analysis of the data (Charmaz, 2001). The key phenomena that emerged were then analysed using axial coding to explore how these key elements of the learning experience related to one another. For example, there appeared to be iterative learning relationships between creating high quality design and reliable sources of research and information, and integrating both these components successfully into the websites. Axial coding also helped to identify the layers and dynamics of learning that occurred including the acquisition of new technological skills and the challenge of communicating effectively using online media. Finally, selective coding was conducted to find a core category that was central to the learning phenomena unearthed in the analysis. This was identified as being an overall *journey from fear to pride*, as students overcame their techno-phobias and felt a great sense of achievement in their final online products.

Findings



Initial Challenges in Integrating Information and Communication Technologies (ICTs) into Assessing Skills in Health Promotion for Women

- **Over-Coming Technophobia**

The key shared response by students as they set about the task of researching, collating and designing for web communication, was that they had never before had to generate health promotion using multimedia, or online in the form of web development. There was a strong consensus amongst the students that fear of the technology was the first step they had to take in bringing this task together. As this student explains:

When I first realized I had to make a website by myself I freaked out. I'm not the most competent computer person and making a website was really something that I did not think I could do. However, after the tutorial where I got everything explained to me on how to hyperlink and link in between pages on the website I sighed of relief as I understood what was expected of me.

Students spoke of the fear lessening over the duration of the semester as their technological skills improved, and they learnt to research and write for the web. One student describes this journey as:

My opinion definitely changed during the time I was making the website. As in the beginning I had no clue how to do it or how to start and in the end I came out with something that was quite fancy for someone who does not know a lot about computers and IT.

Most students concurred that the introduction of using information communication technologies (ICTs) to promote health involved re-thinking the usual learning journey, and being prepared to tackle a new set of skills. This involved overcoming obstacles of fear, self doubt, a lack of self-efficacy in this regard, and an uncertainty that they could achieve the task successfully.

I think that making a website was a very good exercise to do, as you had to overcome an obstacle to be able to make it. But when it was done it was really good and I felt really proud of myself.

- **Desire for New Medium of Assessment**

Students expressed that they found the assessment to be a novelty, in that it was 'fresh way' of assessing their skills in undergraduate Public Health. Many expressed both a desire for and an appreciation of the opportunity to be more creative, to learn new skills and to be tested in new ways – leading to a highly relevant set of skills for their future careers. This student describes the change of assessment as a positive experience:

I learnt a lot by making this website, and I think it is a good alternative to a "normal" assignment (essay, report etc.). You get to be creative and you will most likely improve your computer skills, at least I did.

Another student liked that it was a chance to try out the skills they had already acquired – research and academic writing – in a new communicative forum:

The researching for material is something everyone can do quite easily, as that is what we are taught to do at university. Therefore I think the fact that we made a website was a good change and challenge as the concept was completely new to me anyway.

- **Appreciation of Job-Ready Skills**

Above all, the students reported that this learning journey was one they viewed as important for their positions in the future job-market. They recognized the growing dependence by women on online health information, and were excited at the chance to showcase their research and health promotion skills in a medium that is increasingly relied upon by people to find out about their health.

I think the idea of creating a website was great as I now have a new skill! I also think it was very practical as the world uses the Internet/websites for information more than ever and im sure it will be something I will have to create again in future.

And....

Creating a website of an assessment item is a great idea. It allows students to show that they are not only capable of academic writing, but also have skills in other areas which can be useful for future job positions. It is especially a useful skill to have in public health as most of the jobs available to graduates are in health promotion and being able to promote issues is an important aspect.

Skills and Learning Processes Inherent in Learning to Develop Women's Health Information for the Web

- **Integration of Technical Skills into Women's Health Research**

There were two key pedagogical themes or processes emerging from the data analysis. Students reported that after over-coming the fear they had of a technologically based piece of assessment, one of their primary new skills was knowledge of how to operate new software for the purposes of health promotion and social marketing. They found that the new approach provided them with new sets of skills in ICTs:

It was a different learning process as instead of cramming for a mid semester exam or writing an essay I had to learn Microsoft Publisher which I have never worked with before. I am really pleased that I learned to hyperlink to other websites, between pages on the website and how to add nice pictures.

And...

The key aspect of learning involved for me was most definitely technical skills and learning a new program. Having the ability to design a webpage will certainly be a handy skill to have in this day and age for health promotion and might give me the edge in my future career paths.

- **Health Literacy and Translation into a New Medium**

There were many dimensions involved in learning how to create reliable, high-quality information for women's health issues online, and students reflected on the challenges inherent in finding good sources of data and information, and relaying this in a tone and style that suited the web. This student describes the process via which she learnt to include evidence from peer-reviewed journal articles on her site. She notes a process of translating the research findings into a web-friendly tone and format:

I found it was hard to include research in the information I included within the website. However though conducting interviews and researching journal articles I discovered what information was relevant to include. These aspects included long term outcomes, counseling, preparation and information for partners.

Many students noted the lessons in 'health literacy' inherent in this exercise. This was a practical task for students in taking their knowledge to a public forum and communicating their expertise to a broad range of women who may access the site:

It was also beneficial to do this assignment as it helped me to learn about communication and targeting health literacy to the general population. Throughout university, I have grown accustomed to writing academic reports and essays but this webpage had to be understood by all women.

They also noted the sensitivity with which they had to approach the topic. If the issue was a sensitive one, then the website had to appear supportive as well as informative:

Trying to communicate in the most effective way possible was a challenge. My website was designed for women who found themselves with an unplanned pregnancy. This subject is a controversial one for many and so offering unbiased information on such a sensitive subject was difficult. I found myself often changing the words I was using on the website for less emotive ones so as to appear non-biased.

Reflections on the Current Role of Women's Health Information Online

- **Quality of Information and Communication Style of Women's Health Issues Online**

One of the things students noted early as they researched to see what was available to women online in relation to a number of issues was a general absence of reliable, high-quality information. There is a general lack of evidence based advice offered to women; some of it differs in what is essentially opinion, and some of it is commercially driven. This student noted that:

It is important to know that not all websites out there have up-to-date evidenced based practice and you have to know how to question the information out there. That might be the biggest problem facing the delivery of women's health targeted websites.

Another student noticed the lack of a rationale for a focus on women's health issues on the web. This reflects the lack of a feminist perspective either outlining or driving the case for why women's health is so important. There are many websites advocating women's rights and equalities with men, but this

rationale does not appear to underpin health sites for women. This is notable, as the primary reason for many global health issues facing women are the result of social, economic, and political inequalities, as this student reminds:

There is a lot of information on the Internet however I do not think that they are specifically targeted at women or how women's health can affect every aspect of society and the community.

As well as the need for evidence-based advice for women, and the lack of a strong rationale for a focus on women's health, their appeared that some sites failed in terms of aesthetics, tone, and ease of navigation.

Health literacy should be highly considered when developing any health promotion resource. Websites especially also need to be easy to navigate and should highlight what information they contain so that women can get straight to the information that they are looking for, rather than searching again once they have a site opened.

- **Sensitive Issues, Embarrassment and Privacy Concerns for Women**

The reflections generally reported a key focus on the Internet as both a tool for privacy and liberation for women who were facing health issues that may cause some initial embarrassment or for whom information may not otherwise be readily available. The following three quotes address those issues of the Internet offering a private and socially secure place for initially seeking out information regarding their health:

Women can easily look for information in the privacy of their own homes without any concerns.

And...

I think that the Internet is a fantastic tool for dissemination of health information, particularly for difficult subjects such as that of an unplanned pregnancy, where women may feel very uncomfortable seeking out the information they need in a sphere that is not as private as the Internet.

And...

I think there are many women who may be embarrassed or have other reasons for not seeking professional medical assistance and they may try to use websites or online resources for self diagnosis.

While this student reflected on other barriers women face when seeking information for themselves about their own health, wherein they can access information they would otherwise face barriers in reaching:

Many factors affect women attending health services such as lack of time, lack of money, the embarrassment for some health issues, location and many other factors therefore online health information is an essential service.

- **D.I.Y for Postmodern Grrrls: Everybody is Doing it for Themselves**

Perhaps unsurprisingly, the students thought of searching for health information on the Internet as common-place and unremarkable. They all reflected on their own reliance on the Internet for information about health, and thought that this was a 'common-sense' place to begin researching a personal health issue. While this may well not be the case for older women, or women without Internet access – the number of which is decreasing rapidly in Western countries – it appears to be as valid and natural as using the library may have seemed a decade or two ago. As these students comment below:

I look for health information online, but who doesn't? Every one does in society today

And...

In the contemporary world, there are very few people who don't have some form of access to the Internet, and this is often people's first point of reference when searching for health related information.

And...

Personally, I always 'Google' my symptoms or health issues before I even think about going to see a doctor.

While 'googling' symptoms may be ill-advised and discouraged by the mainstream medical profession, the quick and private availability of what may be useful information for women appears to outweigh the risks that may be associated with this practice. This practice may also be less dangerous than it is currently thought about amongst physicians, as women tend not to use this source of information in isolation, but in conjunction with advice from friends, and consultations with a medical doctor, as this woman explains:

I would seek health information online, but I wouldn't replace it with a health care professional.

However, there are still some women using the Internet only as a means to gain access to face-to-face consultation with a physician. This quote illustrates the broad continuum upon which women rely on 'health advice' from the Internet.

The only 'health info' that I would look for online is to find where the nearest medical centre of sexual health clinic is.

Discussion and Limitations of the Study

The pedagogical reflective data that was analysed in this study sits at the intersection between teaching and research, and provides unique insights into the challenges and barriers to creating and displaying effective and convincing health information for women online. Specifically, it captures the skill-level and capacity of Q.U.T Public Health undergraduates to prepare and present high quality information about women's health issues for use by Australian women on the Internet. While current professional web-designers working for government and private companies would no doubt have their own specific challenges when trying to promote women's health online, it is important in an era where there is an overall 'D.I.Y' philosophy governing web-use, that technological and design

expertise be tested and taught amongst those likely to end up researching and designing health promotion in years to come. The data revealed an emphasis by the students on the importance of being able to have some experience behind-the-scenes of the online interfaces that communicate messages to women about their health and well-being. Due to the highly interactive nature of online communication and general information-seeking activities – as opposed to more passive exercises, such as TV watching – the students showed a high sense of enthusiasm for being able to participate in creating, not just absorbing or analyzing publicly available information about women’s health. Both the literature review and the data in this paper revealed that women are not using the Internet passively or in an undiscerning fashion, and that the potential of online forums to break down current hierarchies traditionally seen in doctor/patient relationships is burgeoning amongst women who use a combination of sources to make their own decisions about their health and their paths of treatment (Sillence et al, 2007; Perez-Lopez, 2004; Ziebland, 2004; Kalichman et al, 2002, Toub, 2001; Fredriksen, 2008; Dey et al, 2008; Pandey et al, 2003. Our findings concur with those in the study by Sillence (2007), who found that when women use the Internet for health information, they sift through websites quickly – being guided by both content and design to decide which information to accept and which to reject. While our study researched the perspectives of the *designers*, as opposed to the *users*, the focus on the importance of getting both the representation of design and content right on each page of their websites was viewed as paramount by the students – who were very aware of how women were likely to use or dismiss their web pages. This is likely to be due to the fact that they reported use of the Internet to research their own health issues, and as public health students, are particularly aware of what constitutes high quality data and resources, and the importance of seeking evidence-based advice from non-commercial sources. As such, this made them discerning creators of women’s health information sources online, as they were acutely aware of research showing a commercial bias in health advice given to women, and how to avoid unreliable-looking websites (Woodlock et al, 2005).

Overall, the students reported a journey that began with high levels of technophobia, and took them through a challenging range of skill acquisition in the fields of technology, visual design, social marketing and health literacy. They felt that the task equipped them with highly relevant skills, reduced their fear levels about future technologically based health promotion efforts, and made them more job-ready than they would have been if they undertook a traditional assessment item in this public health undergraduate subject. The learning processes for the students constituted an iterative cycle between learning new technical and software skills, and being challenged to translate empirical evidence from the highest quality public health research sources into effective communication about health that a broad range of women could understand and follow. The limitations of the study included that we only gained insights from those designing - not using - the websites, and did we did not interview those already working in the field of web development for women’s health to find out what skills may already be out there. However, the study did capture what current public health students know and do not know about how to design contextually sensitive and effective online communication about women’s health, and that while they appeared to have a strong sense of what constituted a good website from a user-perspective, the challenge of developing these websites themselves involved a steep learning curve in technology, communication, health research and online social marketing.

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